Using Q Methodology to Assess Chronic Pain in Elderly Cognitively Intact and Alzheimer's Patients

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Abstract: *Traditional methods such as visual analogue scales, numeric scales, and questionnaires are often ineffective for evaluating pain in cognitively impaired patients. Alzheimer's disease is a progressive neurological disorder that alters various cognitive domains including language and speech, resulting in problems with word finding and concentration. There were 23 elderly participants in this Q Methodology stud, 13with mild to moderate Alzheimer's disease and 10 cognitively intact. Using a 30-card Q set, these individuals were able to communicate about coping with chronic pain. The Q sort process was adapted by individualized explanation and repetition of the condition of instruction. Six uncorrelated factors emerged indicating how all participants described and managed chronic pain. Alzheimer's patients responded more readily using Q sorts than with traditional pain assessment instruments. Possible explanations for this success are explored and further research options are proposed.*

Introduction

When health professionals are faced with the responsibility of caring for an older adult with cognitive impairment, the process of detecting and treating pain becomes particularly challenging and complex. Cognitive impairment related to Alzheimer's disease has been identified as a major barrier to adequate pain assessment (Ferrell, Ferrell, and Rivera 1995; Schmidt-Luggen 1998). Alzheimer's disease is a progressive neurological disorder that alters various cognitive domains including language and speech. This disorder typically inflicts permanent loss of intellectual abilities, personality changes, impaired thinking and judgment along with a decline in memory that is the key indicator. Because cognitively impaired individuals may not be able to articulate their needs adequately, changes in behavior or moaning are often attributed to the Alzheimer's disease itself instead of some pain problem. Poorly detected pain leads to haphazard management and needless suffering.

The inherent subjectivity of pain makes it difficult for clinicians to detect its presence, and cognitive impairment as in Alzheimer's disease compounds the difficulty. No biologic markers, assays, or x-rays confirm the presence of pain. Clinicians typically rely on verbal complaints and behaviors to indicate acute pain, such as restlessness, guarding (protecting the site), crying, sweating (Turk and Melzack 1992); or changes in gait, moodiness, anxiety, and fatigue for chronic pain experiences (Galgliese and Melzack 1997).

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Clinicians seek to measure pain to establish its presence and intensity. They may ask the patient to rate the level of pain intensity using a 0-10 numeric scale. However, individuals with cognitive impairment typically have problems responding to more abstract, conceptual, or numeric scales that attempt to quantify their pain (Parmelee, Smith, and Katz 1993). Improvements in response were noted when researchers provided one-on-one in depth interviews, practice sessions, and more time to respond (Ferrell, Ferrell, and Rivera 1995). In their study, while 80% of the cognitively impaired sample (n=200) could use a numeric pain scale, nevertheless 17% were unable to complete the scale. Even with the additional supervision, if the scale were the only method used to detect pain, 17% would be misdiagnosed or undetected. For individuals with Alzheimer's disease, popular assumptions suggest that the cognitively impaired older adult's reports of pain are invalid or unreliable or that the patient may not have the ability to feel any pain at all (Parmelee 1994).

Given the problems that exist with traditional approaches to pain assessment, clearly a better tool is needed for individuals unable to articulate their pain reliably. Q methodology was selected for this study, since the inherent subjectivity of pain fits well with its philosophy and purpose. Therefore, the purpose of this study was to use Q methodology as an alternative pain assessment tool to obtain a more accurate understanding of how elderly individuals with and without Alzheimer's disease: a). describe their pain behaviors and b). describe what they do to relieve their own chronic pain. It was anticipated that their Q sorts would provide a more comprehensive, patient-derived view of what behaviors and treatments clinicians could expect to observe when patients are having chronic pain.

Methods

Participants

Individuals were selected based upon the following criteria:

1) at least 70 years of age
2) at least 9 years of formal education
3) speak English
4) a history of at least 3 months of nonmalignant chronic pain of musculoskeletal origin, i.e., osteoporosis, osteoarthritis, rheumatoid arthritis, degenerative disk disease, or low back pain
5) mild to moderate cognitive impairment from an Alzheimer's-type dementia, indicated by scoring between 12-23 points on the Mini-Mental Status Exam (MMSE) or
6) no signs of cognitive impairment, indicated by scoring 24 – 30 points on the MMSE.

Concourse Development

A concourse of pain coping behaviors was developed from a review of the literature and focus group sessions. Separate sessions were conducted with mild to moderately impaired Alzheimer patients and cognitively intact elderly. All sessions were audio taped and transcribed. From the discussions and literature review, a list of 173 positive and negative statements of opinion was extracted regarding the behavioral, emotional and self-treatment aspects common to the challenge of coping with chronic pain. The statements were separated into categories: (a) emotional consequences, (b) how others react to my pain, (c) cognitive effects, (d) pain communication, (e) life impact, (f) physical interventions, (g) cognitive interventions. After screening the list for overlap, it was edited to approximately 7 statements per category for a total of 50 statements.

Q set

Each of the 50 statements was written separately in bold, black, 0.25" high lettering on white 3" x 5" index cards to compensate for any age-related visual changes in this older adult population.

Pilot Testing

Since there had been no Q study specifically designed to work with cognitively impaired adults in the past, a pilot study was performed. Pilot testing helped to address the procedural issues related to sorting the cards by elderly people in chronic pain with and without Alzheimer's disease.

Two cognitively intact elderly and 2 impaired elderly participants were asked to sort the cards in order to try to capture how the individuals with chronic pain talked in the focus group sessions about the waxing and waning nature of this pathological condition. Two conditions of instruction were used: "How My Pain Makes Me Feel On A 'Bad' Day;" and "How My Pain Makes Me Feel On A 'Good' Day."

Q sorting instructions were given verbally to each participant. The intact participants were able to read the enlarged font statements and follow directions without difficulty. However, both pilot testers appeared fatigued after completing the Q sorts. The entire session lasted about 60 minutes. They commented that a few statements were very similar and had a difficult time placing the items along the continuum. The male participant stated that after living with it for 10 years, he usually would not like to discuss his pain, but "the cards helped me to say what I feel."

For the 2 cognitively impaired participants, instructions were given individually in a step-by-step fashion. They required periodic reminders to sort the cards as "most unlike themselves" or "most like themselves." The participants were able to read aloud the statements on each card. There was no apparent hesitancy in deciding if the statement was like or unlike them. The male participant would become distracted after sorting about 6 cards, stand up and move around. The female participant looked fatigued. The process lasted about 1 hour and 15 minutes to complete both Q sorts.

Modifications

Based upon the pilot study experience, the Q sample was reduced through editing to 30 cards to help the patients sustain attention and reduce fatigue. The 20 cards that were eliminated had the potential for redundancy and overlap. The editing and culling was accomplished with the assistance of a Q methodology expert and a pain specialist nurse.

Primary Study

Ten cognitively intact and 13 cognitively impaired elderly participants Q sorted 30 statements in a (-4 to +4) format (Table 1) under 2 conditions of instruction: "How the pain makes me feel on a *good* day," and "How the pain makes me feel on a *bad* day." When the Q sorting process was completed, a short interview was held with each individual to determine whether the sort reflected the depth and complexity of the respondent's feelings and to evaluate whether the cognitively impaired individuals were able to distinguish between "good" (low intensity) and "bad" (high intensity) pain days. Anecdotal comments were transcribed.

Forty-six Q sorts were analyzed using PQMethod 2.0 (1997)[1]. Simple structure was obtained with varimax rotation, yielding 6 factors. Q sorts significantly correlated with any factor had a loading of 0.46 or greater on the factor. Q sorts that loaded significantly and purely on a single factor were identified as definers.

Table 1: Q Sorting Format

Value	**-4**	**-3**	**-2**	**-1**	**0**	**+1**	**+2**	**+3**	**+4**
Selections	2	3	3	4	6	4	3	3	2

Results

Table 2: Correlations Between Factors for 6-Factor Solution

Factor	***1***	***2***	***3***	***4***	***5***	***6***
1	1.00					
2	0.43	1.00				
3	0.24	0.37	1.00			
4	-0.10	-0.08	-0.05	1.00		
5	0.27	0.27	0.23	0.23	1.00	
6	0.41	0.40	0.03	0.26	0.33	1.00

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[1] PQMETHOD is a public domain program, which readers can retrieve from the following web site: http://www.rz.unibw-muenchen.de/~p41bsmk/qmethod/. The program is available in both PC and Macintosh versions.

The 6-factor solution accounted for 66% of the variance in the respondent set. Only weak correlations were noted between factors, thereby indicating orthogonality of the viewpoints (Table 2). Factor arrays (Appendix) and composite scores were used to interpret the data by an inductive process. The goal was to describe the ways in which cognitively intact and impaired participants described their own pain behaviors, including their strategies to relieve their pain.

Factor 1: Exercise, Self-Efficacy, and Prayer

This factor had 11 loaders. One of the 5 defining sorts came from a cognitively impaired individual. Factor 1 explains 14% of the variance. This view was associated primarily with "good" pain days. Individuals on Factor 1 employ a combination of physical and cognitive interventions to deal with their pain. There is an emphasis on routine exercise and prayer. Factor 1 indicates the respondent's capability to positively influence the pain experience through a personal proactive strategy. Statement 22, "I can handle it" (the pain), was ranked highest (+4) of all statements on Factor 1, and was agreed with more strongly in Factor 1 than in any other factor. Clinician observers could be expected to see Factor 1 pain patients engaging in active, energetic activities, along with periods of quiet reflection. This is hardly the textbook description of the way elderly cope with chronic pain.

Factor 1: Exercise, Self-Efficacy, and Prayer

No.	***Characterizing Statements***	***Score***
22	I can handle it	4
25	I exercise	4
2	I pray	3
21	I move around and change positions	3
30	I accept the pain	3
12	I don't feel like eating when I have pain	-3
15	I have a hard time thinking when I have pain	-3
19	I lie down	-3
7	I drink alcohol	-4
20	I feel angry	-4

Factor 2: Accepting the Pain as Just Part of Old Age

Nine sorters loaded on this factor. All of the 6 defining sorts were from cognitively impaired individuals. Factor 2 accounts for 12% of the total variance and indicates a strong acceptance that pain is just an expectation of aging. Individuals lie down as well as change positions to help relieve their discomfort. This factor differs from all others in that each of the defining sorts comes from a cognitively impaired respondent. Two respondents generated this factor for both "good" and "bad" pain days. The range of interventions used by patients does not include pain medication. Although these self-relief strategies may be limited in scope, the respondents say that they know what to do to make their pain better.

Factor 2: Accepting the Pain as Just Part of Old Age

No.	Characterizing Statements	Score
19	I lie down	4
30	I accept the pain	4
18	Pain is just a part of old age	3
21	I move around and change positions	3
22	I can handle it	3
5	I rub it	-3
7	I drink alcohol	-3
13	I take pain medication	-3
10	Nothing I do helps the pain	-4
26	I don't know what to do to make my pain better	-4

Factor 3: Sleeping to Escape

This factor had 4 loaders, all of whom were definers. Three definers were cognitively impaired. Factor 3 explained 7% of the variance. This is voiced primarily from cognitively impaired respondents who make it a point to communicate a desire for more information from health professionals.[2] Two of the respondents generated this view on both "good" and "bad" pain days. In this factor, sleep and alcohol are pain relief strategies and, in turn, create a sense of being able to run away from (escape) the pain. Pain medicine is not actively sought for relief.

Factor 3: Sleeping to Escape

No.	Characterizing Statements	Score
9	I sleep.	4
6	I wish the nurses and doctors would tell me more.	4
7	I drink alcohol	3
22	I can handle it	3
30	I accept the pain	3
20	I feel angry	-3
24	I can't run away from it	-3
26	I don't know what to do to make my pain better	-3
5	I rub it	-4
13	I take pain medication	-4

Factor 4: Shutting Down

This factor had 8 loaders. One of the 4 definers was cognitively impaired. Factor 4 explained 9% of the total variance and is created primarily by cognitively intact respondents on "good" and "bad" pain days alike. Unlike the 3 previous factors, pain strongly controls the day's activities. A sense of "shutting down" is invoked using pain medication, lying down, and sleeping. Respondents who loaded on this factor did not feel that pain was an expectation of aging. They let others know about their pain. Exercise was not included as a strategy to combat the pain. Respondents who defined this factor were noted to have particularly flat affects and sluggish movements during the sorting process and subsequent interview. Of all the factors, the respondents who comprised Factor 4 – "Shutting Down" were the most vocal about their pain and demonstrated the most traditional/expected pain behaviors.

Factor 4: Shutting Down

No.	Characterizing Statements	Score
4	The pain dictates what my plans will be for the day	4
13	I take pain medication	4
9	I sleep.	3
19	I lie down	3
30	I accept the pain	3
18	My pain is just part of old age	-3
25	I exercise	-3
27	I apply heat or cold	-3

Factor 5: Acquiescence without Analgesia

Four sorters loaded on this factor. The 3 defining sorts were all from cognitively intact individuals. Factor 5 explained 7% of the variance. In this viewpoint, which is completely defined by cognitively intact respondents, pain is strongly accepted and allowed to take control of the day's activities on both "good" and "bad" pain days without the use of pain medication. A sense of resignation, of submitting or acquiescing to the pain is conveyed; letting the pain direct the activities of the day. Unlike Factors 2, 3 and 4, rest and sleep are not part of this approach to pain management. The day's events may be slowed, but the day is not interrupted purposely by periods of rest or sleep. In fact, the respondents prefer not to be alone. Treatment is limited to moving around and shifting weight off the affected area. Like Factor 3, these patients voiced a need for more information from professional caregivers, but all the loaders on Factor 5 are cognitively intact.

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[2] Whether information has been provided and the respondents do not recall, or health care providers did not provide pain information could not be determined from this sort.

Factor 5: Acquiescence without Analgesia

No.	*Characterizing Statements*	*Score*
30	I accept the pain	4
21	I move around and change positions	4
4	The pain dictates what my plans will be for the day	3
6	I wish the nurses and doctors would tell me more.	3
22	I can handle it	3
13	I take pain medication	-2
9	I sleep.	-3
14	People can tell I'm in pain by my voice	-3
28	I just want to be alone	-3
3	I need someone just to listen and care about me	-4
7	I drink alcohol	-4

Factor 6: Pain Medicine, Movement, and Being with Other People

There were 16 loaders on this factor. Four of the 9 defining sorts came from cognitively impaired individuals. Factor 6 explained the largest percentage of the variance 17%. This viewpoint was derived from both cognitively impaired and intact respondents and the strategy was employed on both "good" and "bad" pain days. Although pain medication figures in as importantly as it does in Factor 4 (Shutting Down), the 2 strategies result in strikingly different behaviors. Instead of lying down and sleeping, the respondents on Factor 6 would be seen moving about, changing position, engaged in activities that involve other people. Examples of post-sort interview comments included "If I can help other people, it helps me forget my pain;" and "I hurt, but I push on." There is a sense of being actively engaged and distracted by other people as a purposeful way to relieve chronic pain.

Factor 6: Pain Medicine, Movement, and Being with Other People

No.	*Characterizing Statements*	*Score*
13	I take pain medication	4
21	I move around and change positions	4
18	Pain is just a part of old age	3
24	I can't run away from it	3
30	I accept the pain	3
7	I drink alcohol	-3
8	I do what I have to for the day, and then I fall apart	-3
12	I don't feel like eating when I have pain	-3
10	Nothing I do helps the pain	-4
28	I just want to be alone	-4

Conclusions

The findings of this study suggest a new approach for how pain can be assessed in patients with Alzheimer's disease. Traditionally, clinicians rely heavily on verbal ideation, repeated vocal complaints, and patient behavioral cues to confirm pain. Based on traditional expectations, only 1 of the 6 viewpoints (Factor 4) would give the traditional impression that the person is experiencing pain. Therefore, the findings of this study identify a new and wider array of active and passive pain strategies and behaviors.

These results also indicate that a Q sort can be an effective alternative method to elicit pain information from elderly individuals with mild through moderate levels of Alzheimer's disease. An unexpected finding emerged in this study: cognitively impaired definers remained loaded on the same factor for "good" and "bad" pain days more consistently than did those in their cognitively intact cohort. This suggests that cognitive impairment might limit a person's ability to change, adapt, or accommodate pain-relieving strategies for "good" and "bad" chronic pain days. From an observer's perspective, the Alzheimer's patients would likely behave in the same manner, from day to day, regardless of pain intensity. This helps to explain the difficulty clinicians traditionally have had in detecting and evaluating pain in this vulnerable population.

Discussion

This study was the first to use Q methodology with Alzheimer's patients with mild through moderate levels of cognitive impairment. Characteristics of the methods in this study that may increase the probability for successful completion of the Q sorting process include:

- focusing attention on 1 card at a time with individual short phrases instead of many lines of print
- self-referenced ideas or feelings make easier targets for patients to respond to instead of abstract numeric or Likert scales
- one-on-one attention received through repeated instruction and post-sort interview
- participants' perception that their thoughts and feelings were valued and could possibly be of benefit to others with similar problems

With Q sorts as a viable mechanism for improved communication with Alzheimer patients, additional work can be proposed.

- Strengthen the clinical utility of Q sorts for patient assessment purposes by developing Q-based instruments that reflect: a) patient satisfaction and physical response to current pain treatments and b) the response to pain complaints by caregivers and health professionals in the presence of dementia.

- Test these instruments in a) acute care and b) home care settings over time from early to middle stages of cognitive impairment.
- On a larger scale, develop a web survey tool to manage and prevent acute exacerbations of chronic pain in elderly individuals. This would entail development of an integrated, electronic communication system to capture the status and perceptions of both Alzheimer-affected and intact elderly patients' pertaining to their chronic pain syndromes. An electronic communication system adapted to the physical and cognitive abilities of this older adult population would provide a mechanism for health organizations to monitor, manage, and track the pain experience. In addition, it would capture the knowledge of elderly patients and caregivers regarding chronic pain and serve as an educational device to address gaps in knowledge, myths, or other misunderstandings.

Although using Q sorting with Alzheimer's patients is labor intensive, the resulting information is rewarding, rich, and meaningful. The use of Q methodology in this study provided new insight into chronic pain detection and a new mechanism for individuals at risk for underdetection to communicate their experience more clearly.

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Appendix

Factor Arrays

No.	*Statement*	*1*	*2*	*3*	*4*	*5*	*6*
1	I don't let anybody know I have pain.	2	0	1	-4	-1	0
2	I pray.	3	0	2	2	-2	2
3	I need someone just to listen and care about me.	0	2	-1	-1	-4	1
4	The pain dictates what my plans will be for the day.	-1	-2	-1	4	3	1
5	I rub it.	1	-3	-4	-2	-2	-1
6	I wish the nurses and doctors would tell me more.	0	-2	-1	4	3	1
7	I drink alcohol.	-4	-3	3	-4	-4	3
8	I do what I have to do for the day, and then fall apart.	0	-1	0	2	-1	-3
9	I sleep.	-1	0	4	3	-3	-1
10	Nothing I do helps the pain.	0	-4	1	0	0	-4
11	I have a hard time seeing clearly when I have pain.	-2	-1	-2	0	0	-2
12	I don't feel like eating when I am in pain.	-3	0	-1	-1	1	3
13	I take pain medicine.	1	-3	-4	4	-2	4
14	People can tell I'm in pain by my voice.	-2	0	0	-1	-3	1
15	I have a hard time thinking when I am in pain.	-3	1	0	0	2	0
16	I don't pay attention to my pain.	2	2	1	-2	-1	-1
17	I wish people would believe me when I tell them I have pain..	-1	-1	-2	-2	0	0
18	My pain is just part of old age.	1	3	0	-3	0	3
19	I lie down.	-3	4	2	3	1	1
20	I feel angry.	-4	-2	-3	-1	-2	-2
21	I move around and change positions.	3	3	2	0	4	4
22	I can handle it.	4	3	3	1	3	2
23	I feel people do not want to hear about my pain.	2	1	1	0	2	0
24	I can't run away from it.	1	1	-3	2	0	3
25	I exercise.	4	2	0	-3	1	-2
26	I don't know what to do to make my pain better.	-1	-4	-3	0	0	-1
27	I apply heat or cold	0	-1	0	-3	1	2
28	I just want to be alone	0	1	-1	1	-3	-4
29	I feel exhausted	-2	0	-2	1	2	0
30	I accept the pain	3	4	3	3	4	3

News, Notes, and Comment

Steven R. Brown Named Editor of *Policy Sciences*

Steven R. Brown has been appointed Editor of the journal *Policy Sciences*, effective July 1, 2001. The journal has been published since 1970 and is among the leading outlets for scholarly work on the policy process. *Policy Sciences* was originally published by Elsevier North Holland, which has counted among its authors the likes of Erasmus and Galileo. The journal was subsequently purchased by Kluwer Academic (Dordrecht, The Netherlands). Kluwer is among the leading publishers in the various fields of science and technology. The journal has often been the most frequently cited of the policy journals. Past editors have been among the most frequently cited scholars in the field. It is presently being edited at Harvard University.

Brown is a founding member of the Society for the Policy Sciences. He has just completed a three-year term on the Society's Executive Council and has been on the Editorial Board for the past three years. He also manages the e-mail discussion lists for the Council and the Society as well as an open list for those with a general interest in the policy sciences.

The term *policy sciences* was originally coined by the political scientist Harold Lasswell (1902-1978) to designate a new intellectual configuration comprised of individuals whose specialties bear on public problems but whose disciplinary boundaries often prevent them from collaborating on solutions. Communication theorists know Lasswell best for his characterization of communication as "who says what, to whom, through which channel, with what effect."

Q methodology has had an informal but growing connection to the policy sciences. Charles Stephenson, for instance, was a student of Lasswell and his collaborator Myres McDougal at Yale Law School. Brown worked with Lasswell and a few of his former students under a National Science Foundation grant in the mid-1970s. Lasswell's work was first mentioned in *Operant Subjectivity* in a study by Baas (1978), and Lasswell's obituary was carried two issues later (April 1979, back cover). *Operant Subjectivity* subsequently hosted policy-science related articles by Scheutzow (1981), C. Stephenson (1983), Brown (1993/1994, 1994a), and another by Baas (1997). Summaries of policy applications of Q were carried periodically in the "News, Notes, and Comment" section. William Stephenson (1987) devoted the entirety of his "How to Make a Good Cup of Tea" to Lasswell's ideas and likened Q factors to Lasswell's decision structures. In the following issue, William Ascher (1987), one of Lasswell's former students, devoted his essay to summarizing the connection between "Subjectivity and the Policy Sciences." The Q community was reminded again of the policy sciences connection when the 1993 ISSSS banquet address was presented by Andrew Willard (1993/1994) of the Yale University School of Law.

On the other side of the coin, Q studies have appeared occasionally in the pages of *Policy Sciences* (e.g., Brown 1974; Brunner and Vivian 1980; Gargan and Brown 1993; Pelletier et al. 1999). The Pelletier paper has just received the Lasswell Award for the best article in the 1999 volume of *Policy Science*. In recent years Q has become more widely appreciated in the policy field. A mini-symposium on Q methodology led off the summer 2000 issue of *Journal of Policy Analysis and Management* (Durning; Steelman and Maguire). The recent volumes by Addams and Proops (2000), Barry and Proops (2000), Peritore (1999), and Van Eeten (1999, 113-42).

The most immediate and obvious advantage Q provides for policy analysts is a rigorous means for determining the perspectives of stakeholders and other participants in the policy process, which is often critical to locating and implementing solutions acceptable to all. It is also useful in value and goal clarification, as Brown illustrated in a keynote address to the Society for the Policy Sciences (1994b). Other policy uses of Q will doubtless be elaborated in the years to come.

The policy sciences approach provides a comprehensive framework for addressing problems of any magnitude and in any subject-matter domain, from psychotherapy to international law, from genetically-engineered food to architecture, from preserving wildlife to space travel, from medical decision-making to the regulation of immigration. Its literature is voluminous, much of it in law books and journals, and dates, as does Q methodology, to the 1930s. Those desiring greater familiarity might begin with Brown's recent essay on "Harold D. Lasswell and the Policy Sciences," which appears in the Winter 2000 issue of *Policy Evaluation* and includes a selected bibliography. A next step would be to attend meetings of the Society for the Policy Sciences, which are held annually at the Yale Law School, New Haven, CT. Additional information can be retrieved from the Society's website, which will be launched soon.

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